

Brief Research Report

An adapted Danish translation of the Center for Neurologic Study Lability scale

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ABSTRACT

INTRODUCTION. Pathological crying and/or laughing (pseudobulbar affect (PBA)) are socially debilitating symptoms seen in many neurological diseases, such as stroke, multiple sclerosis (MS) and amyotrophic lateral sclerosis (ALS). One method for measuring the degree of PBA is the Center for Neurologic Study-Lability Scale (CNS-LS), a seven-item questionnaire validated for quantifying symptoms and supporting PBA diagnoses in ALS and MS. The aim of this study was to provide a Danish translation of the CNS-LS inspired by international guidelines on cross-cultural translation and adaptation of self-report measurements.

METHODS. Through a six-step process, the CNS-LS was translated and back-translated by four certified translators, followed by an expert committee examination. The translation was then field-tested by interviewing patients with ALS and MS after they had completed the CNS-LS. If at least 20% of participants found an item "unclear", it would be reevaluated.

RESULTS. Twelve patients with ALS patients and 30 patients with MS were tested and interviewed. None of the questionnaire items exceeded the 20% threshold for lack of clarity.

CONCLUSION. We present a Danish translation of the CNS-LS to facilitate better diagnosis and quantification of PBA symptoms in Danish patients with ALS or MS.

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TRIAL REGISTRATION. Not relevant.

Pseudobulbar affect (PBA), also known as pathological crying and/or laughing, is a group of motor symptoms seen in neurological diseases affecting the central nervous system [1]. PBA is characterised by a sudden and excessive motor expression of emotion without a clear emotional trigger, resulting in sudden crying and/or laughing in socially improper situations.

PBA has been shown to reduce quality of life, resulting in social isolation and earlier relocation to supervised living facilities [2, 3].

PBA is regarded as an underdiagnosed condition and often misattributed to psychiatric conditions, despite its presence across many neurological diseases with varying prevalence, such as up to 10% of people with chronic stroke, 23% of patients affected by multiple sclerosis (MS), 5% of patients with Parkinson's Disease and 39% of patients with amyotrophic lateral sclerosis (ALS) [1, 2, 4-6].

This calls for the development of valid tools for diagnosis and treatment effects.

Among the verified scales for assessing symptoms of PBA, the Center for Neurologic Study Lability Scale (CNS-LS) is the most frequently employed. The CNS-LS is a seven-item patient questionnaire, originally developed and validated for supporting PBA diagnosis in patients with ALS, with a reported sensitivity of 0.84 and specificity of 0.81 in patients with a CNS-LS score ≥ 13 [7].

It has subsequently been validated for use in patients with MS with a reported sensitivity of 0.94 and specificity of 0.83 for a concurrent PBA diagnosis with a CNS-LS score ≥ 17 [8]. It is now also used in trials and studies of other disease groups [5, 9, 10] and is integrated into the commonly used ALS-rating scale, the PENN-UMN scale [11].

This study aims to provide a usable, adapted Danish translation of the CNS-LS for application in clinical and research settings following international guidelines for the cross-cultural translation and adaptation of self-report measures. [12, 13].

Methods

The method of translation and adaptation was based on guidelines published by Sousa et al. and Beaton et al. [12, 13], which prioritise independent, professional translation and expertise agreement.

The translation process was divided into six individual steps:

Step one: Translation of the original CNS-LS was performed by two independent, certified translators hired through the Danish Association of Certified Translators and Interpreters.

Step two: A version of the Danish translation was created by fusing the two translations. A local committee resolved incompatible translated sections. The previous two translators approved the fused translation.

Step three: Two other independent and certified translators back-translated the new fused version into English to compare it to the original text.

Step four: An expert committee reviewed each of the above-mentioned translated texts and an attached report of the individual translation processes provided by each translator. The committee reviewed each text to determine if the translation comprised any misunderstandings or changes not aligning with the clinical understanding of PBA. Subsequently, a consensus was reached on any discrepancies.

This committee included four medical professionals from subspecialties in neurology. The preceding four translators were consulted if any issues arose as to suspected mistranslations or if the committee found a need to elaborate on specific translation choices.

This led to a pre-final version of the translated text.

Step five: The prefinal version was then field tested in disease groups where the CNS-LS is validated for use, i.e. people suffering from MS and ALS. Field testing included completing the questionnaire and conducting a short interview to determine their understanding of each questionnaire item.

Twelve ALS and 30 MS patients were recruited through the outpatient clinic of the Department of Neurology, Aalborg University Hospital, Denmark, from December 2023 to January 2024.

Patients were recruited through their treating neurologist, who informed them of the project, and gave informed consent after concluding their outpatient visit.

The inclusion criteria were a diagnosis of ALS or MS, the ability to understand Danish and the ability to provide explicit, informed consent.

There were no specific exclusion criteria.

Patients would complete the questionnaire and interview in a room within the outpatient clinic after informed consent had been obtained. In cases where patients could not read the questionnaire independently due to severe physical or visual impairment, the questionnaire would be read aloud to the subject by study personnel.

If a respondent did not understand an item, they were asked to explain why the question was difficult to understand, either in writing or verbally, to the investigator (who then noted the answer).

Proportions of clear to unclear answers for each item were subsequently calculated:

$$\text{Percentage of unclear answers} = \frac{n_{\text{unclear}}}{n_{\text{clear}} + n_{\text{unclear}}} \times 100$$

If at least 20% of answers to an individual item resulted in a misunderstanding, the item in question would be retranslated and retested in the same manner described in steps one through five.

Step six: The final version was agreed upon by the expert committee.

Results

Through steps one through four, a prefinal Danish translation was developed (**Figure 1**).

FIGURE 1 The Danish translation of the Center for Neurologic Study Lability Scale (CNS-LS).

CNS-Labilitetsskala (CNS-LS)

CNS-LS er et kort, 7-punkts spørgeskema skabt til at blive udfyldt af patienter, og som bidrager til et kvantitativt mål af pseudobulbær affekt (PBA) og episoder af PBA. CNS-LS kan anvendes til diagnostisk støtte af patienter, som oplever PBA-symptomer. Den endelig score kan ikke i sig selv diagnosticere PBA, hvor høje eller lave scorere kan ses hos patienter med eller uden PBA.

Navn: _____ Dato: ____ / ____ / ____

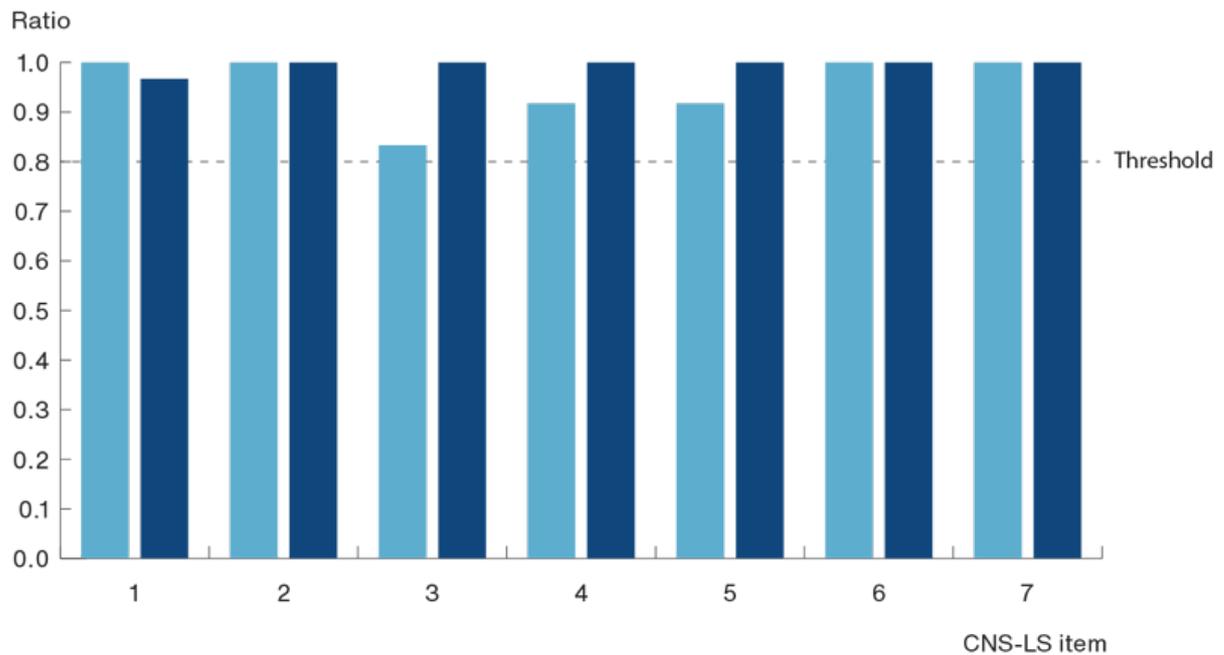
Brug nedenstående skala, og skriv det tal, der bedst beskriver, i hvor høj grad du har oplevet hvert udsagn **I LØBET AF DEN SIDSTE UGE**. Skriv kun ét tal for hvert punkt.

1	2	3	4	5
Aldrig	Sjældent	Af og til	Ofte	Det meste af tiden

Udsagn, du bedes evaluere		Svar (1-5)
1.	Nogle gange har jeg det fint det ene øjeblik, og det næste øjeblik begynder jeg at græde over noget ubetydeligt eller uden nogen grund.	
2.	Andre har fortalt mig, at det ser ud til, jeg meget nemt kommer til at more mig, eller at jeg morer mig over noget, der egentlig ikke er sjovt.	
3.	Jeg synes nemt, jeg kommer til at græde.	
4.	Selv når jeg forsøger at styre min latter, lykkes det mig ofte ikke.	
5.	Nogle gange, hvor jeg slet ikke tænker på noget, der er specielt godt eller morsomt, bliver jeg pludselig overvældet af sjove eller glade tanker.	
6.	Selv når jeg forsøger at styre min gråd, lykkes det mig ofte ikke.	
7.	Jeg synes nemt, jeg bliver overvældet af latter.	

Through field testing of ALS and MS groups (referred to in step five), the following clarity ratios for each questionnaire item were established (**Figure 2**).

FIGURE 2 Clarity ratios^a of each Center for Neurologic Study Lability Scale (CNS-LS) item from amyotrophic lateral sclerosis (■) (n = 12) and multiple sclerosis (■) (n = 30) groups. The threshold for an acceptable ratio (0.8) is noted.



a) "Clear"-answer/no. of participants.

All items exceeded the necessary 80% threshold, and no further edits of the translated text were needed to produce the final version (step six).

Discussion

Even though current and referenced international guidelines guided the method described, some key elements were lacking due to population sizes and feasibility. Ideally, 40 patients from each disease group should be field tested in step five to achieve the recommended statistical power, and at least ten patients are regarded as necessary, according to guidelines by Beaton et al. [12].

We consider that the above process contains important steps towards validating the translation of a questionnaire. However, it did not include the final step for cross-cultural validation. To do so, further field testing of the translated test would be recommended with bilingual testing and, ultimately, full psychometric testing. This final step would require a total sample size of 300-500 subjects for each disease group to follow recommended guidelines. Unfortunately, this is not feasible for patients with ALS in Denmark and was therefore not part of this study.

Conclusion

Using recommended translation and adaptation guidelines, we translated, committee reviewed and field-tested the CNS Lability Scale to Danish for research and clinical use of PBA measurement for patients with ALS and MS. Although strictly adhering to cross-cultural validation steps may produce a fully validated scale in Danish, we contend that the current version will serve as the standard and freely available Danish translation of the CNS-LS

for clinical and research use, as opposed to previous site-specific ad-hoc translations.

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The original English version and the above Danish translation are freely available for clinical and research use.

References can be found with the article at ugeskriftet.dk/dmj

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